



Original article

Overcoming diabetes-related stigma in Iran: A participatory action research

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ABSTRACT

Objective: The study aimed to overcome diabetes-related stigma in individuals living with type 1 Diabetes Mellitus (T1DM) in Iran. The study proposed that if individuals with T1DM and the community work together to develop and implement an anti-stigma program, diabetes-related stigma in individuals with T1DM can be reduced.

Research design and method: This study was conducted as a participatory action research study based on Kemmis and McTaggart's (2000) Model to design and implement an anti-stigma program for T1DM. Participants were selected among individuals with T1DM, their family members, health care providers, and residents without diabetes in Isfahan, Iran. Data collection was conducted using interviews, focus groups, emails, and text messages. Content analysis was used to analyze the data to develop anti-stigma interventions. Interventions were prioritized based on the Suitability, Feasibility and Flexibility (SFF) Matrix. Anti-stigma interventions were implemented in different levels in Isfahan, Iran, from 2011 to 2014. The effect of the program was evaluated based on interviews, feedback, and focus groups at the individual level. However, interventions were implemented in different levels including community, organization, family, and individual.

Results: Participants with T1DM experienced significant empowerment during the project to overcome diabetes-related stigma. The three main themes indicating this feeling of empowerment are “from doubt to trust”, “from shadow to light”, and “from me to us”.

Conclusion: Participatory action research can be an effective way to reduce diabetes-related stigma in individuals living with T1DM. It integrates the voices of the marginalized group reducing stigma and discrimination against diabetes.

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1. Introduction

Individuals with a stigmatized condition can move from a “normal” to a “discredited” or “discreditable” social status (Goffman, 1963). Health-related stigma is typically characterized by social disqualification of individuals and populations who are identified with particular health problems (Weiss, Ramakrishna, & Somma, 2006).

In the 21st century, diabetes-related stigma has become an important issue in many countries around the world. There is a large amount of evidence of people experiencing stigmatization and discrimination in the U.S (Kruger & Spollett, 2009; Pyatak, 2010), Ireland (Balfe et al., 2013), Canada (Nurmi & Stieber-Roger, 2012), Australia (Browne et al., 2014), India (Kesavadev et al., 2014), and China (Jaacks et al., 2015). The results of the DOWN2 study in 17 countries involving 8596

participants with diabetes highlighted that 46% of individuals experienced negative psychosocial well-being related to diabetes. Stigma and discrimination were also identified as one of two major psychosocial challenges in living with diabetes (Stuckey et al., 2014).

Evidence shows that people with diabetes in Iran also experience stigmatization and discrimination like many other countries. The secondary findings of several Iranian workers pointed to the experience of diabetes-related stigma in Iran (Abdoli, 2008; Abolhasani, Babaie, & Eghbali, 2008; Doosti Irani, 2006). A recent study was conducted in Iran to explore the features of stigma associated with T1DM. It revealed that a person with T1DM is stigmatized as a miserable human (always sick, unable, a death reminder, and an intolerable burden), deprived of a normal life (prisoner of “to must” and deprived of pleasures), and a rejected marriage candidate (because of a busy spouse or a high-risk pregnancy) (Abdoli, Abazari, & Mardanian, 2013).

Diabetes-related stigma may preclude self-care (Mulvaney et al., 2011; Salamon et al., 2010); diabetes adherence (Mulvaney et al., 2011); general health-seeking behaviors (Jaacks et al., 2015); and

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insulin injection in unsanitary places (Abdoli et al., 2013; Browne et al., 2014; Shiu, Kwan, & Wong, 2003).

Quality of life and quality of care improvement in diabetes necessitates overcoming diabetes-related stigma through developing and implementing appropriate anti-stigma strategies (Abdoli et al., 2013; IDF, 2011; Schabert et al., 2013). The aim of this study was to reduce diabetes-related stigma in individuals with T1DM in Iran.

2. Research design

This study applied participatory action research based on the Kemmis and McTaggart Model. Participatory research is an alternative philosophy of social research (and social life) often associated with social transformation in developing countries. It is rooted in liberation theology and neoMarxist approaches to community development, but also has liberal origins in human rights activism (Kemmis & McTaggart, 2000). This study was conducted in four stages including plan, act, observe, and reflect (Fig. 1) based on the Kemmis and McTaggart (2000) Model from 2011 to 2014 in Isfahan, Iran. Each stage will be discussed based on the Kemmis and McTaggart approach in more detail.

3. Description of specific stages

3.1. I - First stage: planning

The aim of the first stage was to involve young adults with T1DM, the public, and health care providers in developing anti-stigma interventions. The main diabetes research center, affiliated to Isfahan University of Medical Sciences, agreed to collaborate in this study. Research fliers and posters were distributed at the diabetes center and in the Isfahani community. Individuals who had medical history or records at the diabetes center were contacted directly by P.I (M.D.I) and selected using convenience sampling. Inclusion criteria included people living with T1DM that were 18 years old or older, lived with T1DM for a minimum

of 1 year, and willing to attend the study to share their experiences. Exclusion criteria included people with a psychiatric disorder or unable to share their experiences. The inclusion criteria for individuals without diabetes (with or without having a family member with type 1 diabetes) were willing to participate at the study. All health care providers at the diabetes center were eligible because of their experience in diabetes care. After considering the inclusion and exclusion criteria, 75 participants attended the study to develop anti-stigma interventions for T1DM in Isfahan, Iran. Forty-four participants were individuals with T1DM (19–50 years-old with 2–35 years of experience living with diabetes; 25 female and 19 male, secondary to PhD), 12 family members of people with T1DM (22 to 60 years-old; 2 male and 10 female, elementary to BS), 15 individuals without diabetes from community (18–60 years old, 9 females and 6 males, elementary to BS), and 4 health care providers (26–50 years old with 5–28 years of experience in diabetes care; 4 female, BS to MD).

3.2. Developing anti-stigma interventions

The participants attended 27 individual face-to-face interviews, 14 phone interviews, and 10 focus groups to develop anti-stigma interventions for diabetes. They also had the chance to share their ideas with the research team through emails ($n = 11$) and mobile text messages ($n = 97$). All interviews were audiotaped and transcripts were made immediately after each interview or focus group. All of the data was analyzed using qualitative content analysis (Elo & Kyngäs, 2008). Participants developed 4 levels of anti-stigma interventions including community (public education, contact, protest, and advocacy) (Doosti Irani, Abdoli, Iraj, Parvizy, & Seied, 2014), organization (changing diabetes care approach and changing diabetes centers policies), family (empowering the family of individuals with T1DM), and individuals (empowering individuals with T1DM) (Doosti Irani, Abdoli, Parvizy, Seied Fatemi, & Amini, 2015) (Table 1).

4. Community level anti-stigma interventions

4.1. Public education

Participants believed that public education, with appropriate content through different channels, could help the public realize that diabetes is a manageable illness and individuals with diabetes can have a normal life.

Table 1
Anti-stigma interventions for T1DM in Isfahan, Iran.

Community level	Public education	Public education with Appropriate content Public education through different channels
	Contact	Indirect contact Direct contact
	Advocacy	Revised employment laws Access to health care Media critics/media watch
Organization level	Protest	Shift to humanistic diabetes care approach
	Change in diabetes care approach	Shift to individualized diabetes education approach Health care providers update about diabetes care and education
Family level	Change in diabetes centers policy	Making diabetes centers more positive
	Empowering family members	Reducing waiting time at diabetes centers Family education to help eradicating stigma Family support group
Individual level	Empowering individuals with T1DM	Education of required skill for diabetes life
		Peer support group

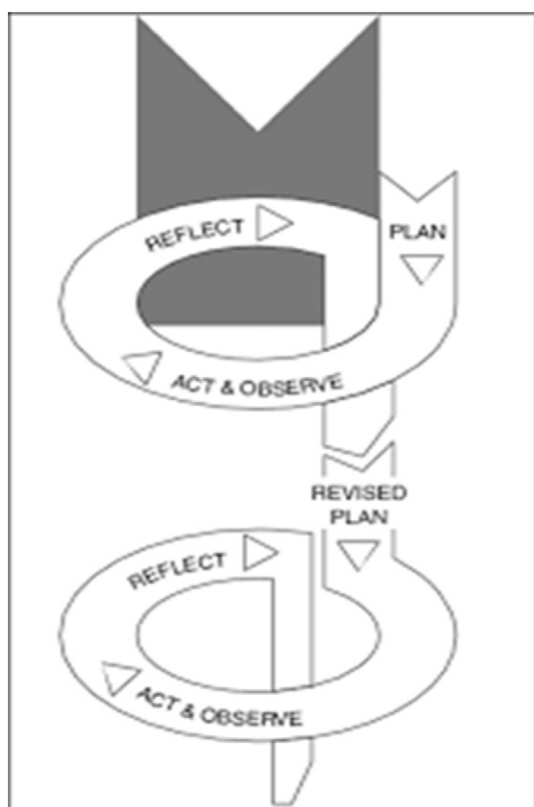


Fig. 1. Action research spiral. Action research spiral, adopted from (IDF, 2011).

"People do not know what diabetes is really, what are the manifestations of hypoglycemia... one day I experienced hypo on the street, I was not able to balance... Police officer came to me as a drug abuser. I was surrounded by people talking about me as a drug abuser... They know about drug abuse because there are many different TV shows, series, and many related news in newspaper... but they do not know about diabetes because there is nothing to say about hypoglycemic manifestations of diabetes which does not have any connection to drug abuse. It is just diabetes and you can manage it... If they understand it, they will not stigmatize us ..." (Male 23 years old with diabetes).

4.2. Contact

Providing the opportunity of contacting individuals with T1DM using the public and the community was another intervention suggestion. Participants believed that direct or indirect contact with the community could help open the public's mind about the life of those living with diabetes, showing that people with diabetes can have a normal life.

"Introducing people with type 1 diabetes with the ability to manage diabetes with physical and psychological health at the media can be a great way to show public that people with diabetes can have healthy life..." (Female health care provider, 35 years old).

4.3. Advocacy

Advocacy of an individual's right for employment and access to the health care was another significant anti-stigma intervention. Participants believed that advocacy could help stop stigmatization and discrimination against those with diabetes.

"Government-related organizations do checkup before employment... and if you have diabetes they will not employ you... my first suggestion comes back to the government... they should support us... when public see we can go to the same university that they go... we can do the same job that those without diabetes can do... they will gradually change their stigmatized attitude towards those with diabetes..." (Female with diabetes, 22 years old).

4.4. Protest

Participants suggested protest as another anti-stigma intervention at the community level. This would be accomplished through writing critical reviews for TV series and shows to change public attitude about T1DM.

"Writing critic reviews on TV series or news at newspaper about diabetes in a helpful way... however; they only talk about diabetes complications such as amputation, kidney disease, etc..." (female with diabetes, 23 years old).

5. Organization level anti-stigma interventions

5.1. Changing diabetes care approach

Participants suggested that health care providers are supposed to be supportive, knowledgeable, and facilitate the empowerment of individuals with diabetes. However, health care providers sometimes reinforce the stigma against people with diabetes. The participants thought the current approach in diabetes care and education needed to change.

"Please ask them to do not always advise us... We need their understanding... We need their support... We face many stressful situations in our daily life and do not want to be blame for our high blood sugar... Please ask them do not just talk about diabetes-related chronic complications to scare us... Please train them to be more supportive and give us hope and positive energy..." (male with diabetes, 23 years old).

5.2. Changing diabetes centers policy

Participants stated that the policy of diabetes centers needed to change to provide a supportive and understanding environment:

"If diabetes centers hired individuals with diabetes, it can help to reduce stigmatization and provide more understanding environment. Employee with diabetes have a good knowledge about diabetes and can communicate better with the clients...on the other hand, public can see those with diabetes can work so it helps to reduce stigmatization." (Male without diabetes, 25 years old).

6. Family level interventions

6.1. Empowering family of individuals with T1DM

Participants talked about frequent support given from family; however, they experienced stigmatization from the family and therefore discussed family education about stigmatizing behaviors.

"Family members should know their child is the only responsible for diabetes management... Their child needs to manage his/her diabetes without parents' direct and close attention. It seems they always look at their child through a specific lens to be sure they are doing good..." (Female without diabetes, 28 years old).

Organizing family support groups was another suggested useful strategy to empower the family members and increase their coping strategies of having a child with T1DM.

"My mom always has stress and calls me and says are you OK my baby? Do you have any problem (female with diabetes, 23 years old)... My Mom is the same, she always calls me at the morning (female with diabetes, 22 years old)... I think it is a good idea for our families to meet each other as a group (female with diabetes, 27 years old)..." (Focus Group).

7. Individuals level interventions

7.1. Empowering individuals with T1DM

Participants believed that accepting the diagnosis of diabetes and being educated about how to live a better life with diabetes can help people to not stigmatize themselves and respond better to social stigma.

"Individuals with diabetes need to accept their disease, themselves as those living with diabetes.... to consider diabetes as a friend not an enemy... they need to do not pity for themselves, to learn about diabetes, to take care of their diabetes,... in that case society will not stigmatized them because they believed themselves, their abilities and can manage diabetes..." (Female with diabetes, 28 years old).

Being part of a peer group where people can share their experiences about T1DM was another strategy that was developed.

"Having meetings with the peers is wonderful... where you can talk about your life with diabetes in a simple way with those who are exactly like you and can understand you..." (male with diabetes, 21 years old).

7.2. Priorities of anti-stigma interventions

Every intervention was scored by the participants based on the SFF matrix in terms of importance, feasibility, and flexibility of each intervention (1 = Low and 3 = High). Each intervention had a score between 3 and 9. Overall, community interventions had the highest score and individual interventions had the lowest score; however, the scores were close to each other and the differences were not significant (Community level = 6.76, Organization level = 6.74, Family level = 6.60, Individual level = 6.58).

7.3. II - Second stage - act

To implement the developed interventions researchers and participants worked on funding and support from different organizations in

the community to implement the most important and feasible anti-stigma interventions in Isfahan, Iran.

Isfahan University of Medical Sciences, Isfahan Endocrinology and Metabolism Center, College of Nursing and Midwifery, Isfahan Municipality, Isfahan broadcast, Isfahan Local Newspapers, Novo Nordisk, Sanofi Aventis, Camvar food company, nursing, midwifery and medical students and faculty members along with the participants have actively collaborated to implement different interventions. All interventions were developed, designed, and implemented based on the participants' suggestions and their active collaboration.

8. Community level interventions

8.1. Diabetes walking tour

The first diabetes walking tour was organized in Isfahan during Diabetes World Week in 2011. More than 800 members of the public attended the tour, and many individuals with T1DM attended. People who attended the walking tour received pamphlets and booklets about diabetes, diabetes self-management behaviors, and local support resources (*Photo 1*).

8.2. Diabetes parade

The Diabetes parade has taken place during Diabetes World Week for the past two years. Individuals with T1DM along with diabetes educators, nursing, midwifery and medical students, and faculty travelled in buses to the community to measure public blood sugar and BMI, educate the community about diabetes, and correct their misunderstanding about diabetes and insulin. Some of the main messages in the Parades were “insulin injection is not addiction”, “diabetes is not contagious”, “Diabetes is a manageable illness”, and “Diabetes is not a barrier for marriage and employment”. Individuals with T1DM collaborated actively to educate the public, measure their blood sugar, and show them that they can live with diabetes without having blindness or amputations (*Photo 2*). We did not have the correct information about the total number of people without diabetes who referred to the buses in first parade, but 1200 people without diabetes were referred to the second parade.

8.3. Diabetes education in community centers

More than 2000 residents in Isfahan received 21 free diabetes education sessions provided by graduate nursing and medical students based on an approved content. The sessions focused on providing information about diabetes, different types of diabetes, diabetes self-management, and misunderstood beliefs surrounding diabetes and individuals with

diabetes. Individuals with type 1 diabetes attended the sessions to make connections with members of the public.

8.4. Diabetes education at local newspaper

An interdisciplinary team including nursing faculty, endocrinologists, nutritionists, and psychologists regularly published scientific information about diabetes, diabetes self-management, and diabetes-related stigma in an Isfahan local newspaper.

8.5. Media critics group

Individuals with T1DM developed a group to talk about TV series and shows related to diabetes as well as considering news published at national and local newspapers to criticize their stigmatized aspect. Participants published their critique about two TV series in the local newspapers. They also sent two official letters to the local newspapers and the media trying to encourage them to change their language while talking about those living with diabetes. Individuals with diabetes asked for using the word “people with diabetes” instead of “diabetics”. Here is one of their critiques on the TV series:

8.5.1. From diabetic coma to community coma

“Yadavari series was a good story... a story about those with a second chance for life... A child with type 1 diabetes went to diabetic coma because of not controlling diabetes but comes back again to life... It is exactly true that ignoring diabetes management can lead diabetic coma and affects the individual, the family and the community... but I wish instead of considering diabetic coma, the TV series looked at community coma about diabetes... Where people do not know anything... Where they stigmatized the person as a miserable, sick and disable one... who cannot work, who cannot have healthy child... it was wonderful if this series showed community can go to a coma by ignoring the abilities of those living with diabetes and by stigmatizing them...”

9. Organization level interventions

9.1. Podium about stigma at local diabetes conferences

Individuals with diabetes and the researchers had the opportunity to take the podium to discuss diabetes-related stigma and health care providers in two local diabetes conferences. More than 500 healthcare providers attended each conference. Individuals with T1DM presented information about diabetes self-management at the conferences where different health care providers and local diabetes policy makers



Photo 1. Diabetes walking tour.



Photo 2. Diabetes parade.

were present to hear them. The main message of the conference was **“without stigma the world of diabetes is more beautiful”** (Photo 3)

9.2. Diabetes education CD's for kids

After review of different diabetes education materials in Persian, there were two attractive and useful CDs for kids selected. All of the kids with T1DM and their families had the chance to benefit from these educational materials about living with diabetes.

9.3. Making diabetes center environment more positive

Several posters and billboards with positive sentences about life with diabetes or pictures about life and nature were put in different areas of the diabetes center. Researchers and participants prepared the messages, and the chief of diabetes center confirmed them. One staff member in the diabetes center was responsible to put messages on the billboards and change them periodically.

10. Family level interventions

Regardless of advertising the diabetes education class and developing the support group for families of the participants with type 1 diabetes; the recruitment did not go well. However, few family members attended diabetes education sessions for the individuals with type 1 diabetes.

11. Individuals level intervention

11.1. Diabetes Self-Management Education

Individuals with T1DM attended a series of 16 Diabetes Self-Management Education sessions provided by an interdisciplinary group including nurses, nutritionists, endocrinologists, family medicine, and biomedical engineers. The content of each session was selected based on the specific needs of the participants. The content included “healthy diet and carbs count”, “adjusting insulin”, “insulin pumps”, “advances in diabetes treatment; islet and pancreas transplantation”, “physical activity”, “management of acute diabetes complications”, “management of chronic diabetes complications” (Photo 4).

11.2. Believe yourself sessions

Individuals with T1DM attended eight **“believe yourself”** sessions provided by two psychologists, with different groups for men and women. Participants had the opportunity to carefully look at their concerns in living with diabetes and reflect on their problem-solving strategies. The aim of these sessions was to help the participants gain a better understanding about themselves, to manage their stress and increase their coping skills to integrate diabetes into their identity, and consider their abilities and their positive aspects of their life. Each person had the chance to talk about his or her experience of stigmatization and discrimination in living with diabetes such as being a rejected marriage candidate.



Photo 3. Podium about stigma at local diabetes conferences.



Photo 4. Diabetes Self-Management Education.

It is necessary to mention that we first decided to incorporate sessions about diabetes management and psychological issues, but because of several reasons they were separated. The main reason was that participants with T1DM requested separated sessions. The second reason was that psychologists requested small same-sex groups for their discussions so we had to categorize participants for them. The third reason was it was very difficult to set a time for psychologists and diabetes educators to attend simultaneously. We did not observe any negative effects of this separation so it seems like a good idea to continue with this separation in future.

11.3. Picnic day

Individuals with T1DM selected a peer to organize picnic day. They had a chance to meet each other in a friendly environment outside of the diabetes center to talk about their challenges and solutions in living with diabetes, and in particular diabetes-related stigma.

11.4. Blue chain

Each person was connected to two different people called senior and junior diabetes peers. The diabetes peers were diagnosed with diabetes before or later than the other person. Peers were selected and introduced by researchers. All peers participated in an introduction session and the series of 16 Diabetes Self-Management Education sessions. They were requested to call diabetes educators and researchers if they had any problems. These three peers had the opportunity to meet, call, or send texts to each other about their life with diabetes and their daily challenges. However, during the study they developed friendship and made a wider chain.

11.5. Diabetes and Life weblog

“Diabetes and Life” weblog was developed in collaboration with individuals with diabetes, health care providers, and the research team. The aim was to connect individuals with type 1 diabetes around the country. It was also a place to share their experiences, challenges, and knowledge about diabetes, diabetes self-management, and diabetes stigma. The main message of the weblog was: **“look at me, not my diabetes”**

11.6. III - Third and fourth stages - observe and reflect

After implementing each intervention, the group met regularly to reflect on the process and outcomes of each intervention. They also had the chance to give their feedback on each intervention through text or email. To evaluate the effects of each intervention, we focused on all recorded meetings during this process as well as narratives and stories that people with diabetes returned to us. We have developed a diabetes-related questionnaire according to the meaning of diabetes-related stigma in Iran, but unfortunately it was not ready at the time of action research. During the observation and reflection stage in a participatory action research the researchers should discuss the effect of the project on their participants qualitatively. In further research, we hope to

evaluate it based on our questionnaire. It seems necessary to develop a questionnaire to assess the mean of diabetes-related stigma among people without diabetes after anti-stigma interventions.

11.7. How this project affected the participants?

All the participants with type 1 diabetes experienced a positive move forward during this project. They felt they had become more empowered in living with diabetes and in eliminating diabetes-related stigma. Although the participants with T1DM described this movement with different sentences in their narratives, it was a common finding in their narrative.

11.8. From doubt to trust

In the initial interview participants did not trust the project. They considered the project a research study, and the research team as outsiders whose only aim was to complete a project for their professional benefits.

“I didn’t aim to come to this meeting, because nobody does really concerns about us, they just come and go to do their own research project...” (Female with diabetes, 22 years old).

While the project moved forward, participants gradually integrated themselves more in the process. They started to think seriously about anti-stigma strategies and always had time to attend different meetings.

“I believe that we can make a difference together...our main concerns are marriage and employment opportunity for individuals with diabetes. If you have a meeting let me just know. I always have time for this project...” (Male with diabetes, 36 years old).

They developed a sense of belonging to the project. They used some words, verbs, and sentences in their conversations indicating this was their own project and not just a research study (for example; in our last diabetes parade...). In fact, a sense of trust developed during the 3 years this project took place.

11.9. From shadow to light

They gradually changed their approach and how they respond to diabetes-related stigma. At the initial stage of the project many of the participants indicated that diabetes is one of their biggest life secrets. They tried to hide it from others, including their parents or family members.

“My husband’s family does not know about my diabetes... it is my husband and I secret...they do not know that I inject insulin... I always hide my insulin in a place and I am thinking how long I am able to hide it...” (female with diabetes, 28 years old).

During the project they moved from the shadow toward the light. However, aware of social stigma, they did not try to hide their diabetes. At the end of the project one of the participants said:

“Now I do not have any stress to disclose my diabetes...I am not scary if somebody sees me while injecting insulin... now I think we, (individuals with diabetes) are the main recourse of stigma... if we change our mind, we can overcome social stigma in our community ...” (Female with diabetes, 29 years old).

11.10. From me to us

The participants made friendships with their peers. They were not alone anymore. They have connected to a group of individuals with type 1 diabetes. They named themselves as members of the **Blue Circle**, which is a symbol of diabetes around the world. A 27 year old male with type 1 diabetes said:

**“...several times I told myself aloud
If you do not have any power don't be sad
There is always HANDs
Use your HANDs...
Take the mountain away from the road like a light feather...
And how amazing power it is; the HANDs holding each other...”**
(Fereydoon Moshiri, Persian Poet).

During the study, we found that all participants approaching us such as drop water. They gradually connected to each other and moved as a river. The positive forward movement of this river was so highlighted that it could be mentioned as the main effect of the study on the participants. Many people participated in this study, but on one hand not all of them joined us at the same time. Some people did not join because of time and cost limitations, so we decided not to distribute any questionnaires to assess their knowledge about diabetes. If we did, we could have measured the effects of our education on people with and without diabetes. However, after some interventions in the community we observed qualitatively that people without diabetes were asking some deep questions about diabetes and how to correctly manage it. These questions showed that they were thinking about different aspect of diabetes on the affected people, and now they know that diabetes is manageable and not a disaster. Such qualitative observations motivated participants with diabetes to move with more energy. This reflects the effectiveness of action research.

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Conflict of interest

There is no conflict of interest.

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References

- Abdoli, S. (2008). *Empowerment in people with diabetes*. Thesis for PhD in nursing Shahid Beheshti University of Medical Sciences.
- Abdoli, S., Abazari, P., & Mardanian, L. (2013). Exploring type 1 diabetes-related stigma. *Iranian Journal of Nursing and Midwifery Research*, 18(1), 65–70.
- Abdoli, S., Doosti-Irani, M., Parvizi, S., Seyed Fatemi, N., Amini, M., et al. (2013). Living in the shadow and light: Iranian youths' responses to diabetes-related stigma. *European Online Journal of Natural and Social Sciences*, 2(2), 439–448.
- Abolhasani, S., Babaie, S., & Eghbali, M. (2008). *Mothers experience about self care in children with diabetes*. Isfahan University of Medical Sciences.
- Balfe, M., Doyle, F., Smith, D., Sreenan, S., Brugha, R., Hevey, D., et al. (2013). What's distressing about having type 1 diabetes? A qualitative study of young adults' perspectives. *BMC Endocrine Disorders*, 13(25).
- Browne, J. L., Ventura, A., Mosely, K., Speight, J., et al. (2014). 'I'm not a druggie, I'm just a diabetic': A qualitative study of stigma from the perspective of adults with type 1 diabetes. *BMJ Open*, 4 (e005625).
- Doosti Irani, M. (2006). *Lived experience of people with type 2 diabetes*. (Thesis for master degree in nursing) Isfahan: Isfahan University of Medical Sciences.
- Doosti Irani, M., Abdoli, S., Iraj, B., Parvizi, S., & Seied, F. M. (2014). Strategies to overcome diabetes-related social stigma. *IJNMR*, 19(5).
- Doosti Irani, M., Abdoli, S., Parvizi, S., Seyed Fatemi, M., & Amini, M. (2015). Breaking stigma within us: The role of people with type 1 diabetes. *International journal of diabetes in developing country*.
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62, 107–115.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*.
- IDF (2011). *Global Diabetes Plan: 2011–2021*.
- Jaacks, L. M., Liu, W., Ji, L., Mayer-Davis, E. J., et al. (2015). Type 1 diabetes stigma in China: A call to end the devaluation of individuals living with amangeable chronic disease. *Diabetes Research and Clinical Practice*, 107, 306–307.
- Kemmis, S., McTaggart, R., & Lincoln, Y. (2000). Participatory action research. In N. Denzin (Ed.), *Handbook of qualitative research* (pp. 567–605) (2nd ed.). Thousand Oaks, CA: Sage.
- Kesavadev, J., Sadikot, S. M., Saboo, B., Shrestha, D., Jawad, F., Azad, K., et al. (2014). Challenges in type 1 diabetes management in South East Asia: Descriptive situational assessment. *Indian Journal of Endocrinology and Metabolism*, 18(5), 600–607.
- Kruger, D. F., & Spollett, G. R. (2009). Addressing barriers to timely intensification of diabetes care: The relationship between clinical inertia and patient behaviour. *Consultant*, 49, S20–S25.
- Mulvaney, S. A., Hood, K. K., Schlundt, D. G., Osborn, C. Y., Johnson, K. B., Rothman, R. L., et al. (2011). Development and initial validation of the barriers to diabetes adherence measure for adolescents. *Diabetes Research and Clinical Practice*, 91(4), 77–83.
- Nurmi, M. A., & Stieber-Roger, K. (2012). Parenting children living with type 1 diabetes. *The Diabetes Educator*, 38(4), 530–536.
- Pyatak, E. A. (2010). *Diabetes management in the everyday lives of emerging adults* (Thesis for University Of Southern California).
- Salamon, K. S., Hains, A. A., Fleischman, K. M., Davies, W. H., Kichler, J., et al. (2010). Improving adherence in social situations for adolescents with type 1 diabetes mellitus (T1DM): A pilot study. *Primary Care Diabetes*, 4(1), 47–55.
- Schabert, J., Browne, J. L., Mosely, K., Speight, J., et al. (2013). Social stigma in diabetes: A framework to understand a growing problem for an increasing epidemic. *Patient*, 6, 1–10.
- Shiu, A. T. -Y., Kwan, J. J. Y. -M., & Wong, R. Y. -M. (2003). Social stigma as a barrier to diabetes self-management: Implications for multi-level interventions. *Journal of Clinical Nursing*, 12, 149–150.
- Stuckey, H. L., Mullan-Jensen, C. B., Reach, G., Kovacs Burns, K., Piana, N., & Vallis, M. (2014). Personal accounts of the negative and adaptive psychosocial experiences of people with diabetes in the second Diabetes Attitudes, Wishes And Needs (DAWN2) study. *Diabetes Care*, 37, 2466–2474.
- Weiss, M., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: Rethinking concepts and interventions. *Psychology, Health & Medicine*, 11(3), 277–287.